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ABSTRACT

This booklet contains guidelines to help families coordinate health care of a child with diabetes. The first section provides general information covering what diabetes mellitus-Type I is, the symptoms of diabetes, causes of Type I diabetes, and effects of diabetes. A section on health care focuses on the membership and functions of the Family Centered Health Care Team, periodic health care, and recordkeeping. The next section breaks down the diabetic child's health care needs, proper development, schooling, and day care for each of the following age groupings: infants ages 0-2, preschool children ages 3-5, school-age children ages 6-12, adolescents ages 13-17, and young adults ages 18-21. The next section briefly describes family support services including advocacy, schools, family support groups and networks, recreation, respite care, safety, and siblings. A glossary of 41 diabetes-related terms is provided. A listing of resources includes 6 diabetes-specific organizations; 23 books, pamphlets, and videos for children and families; 19 articles and books for health professionals; 7 resources (in Minnesota) for specialty medical care for children with diabetes; 21 general organizations for children with special health care needs; 20 general books, pamphlets, videos, and catalogs; and 7 sources of health care financing. (DB)

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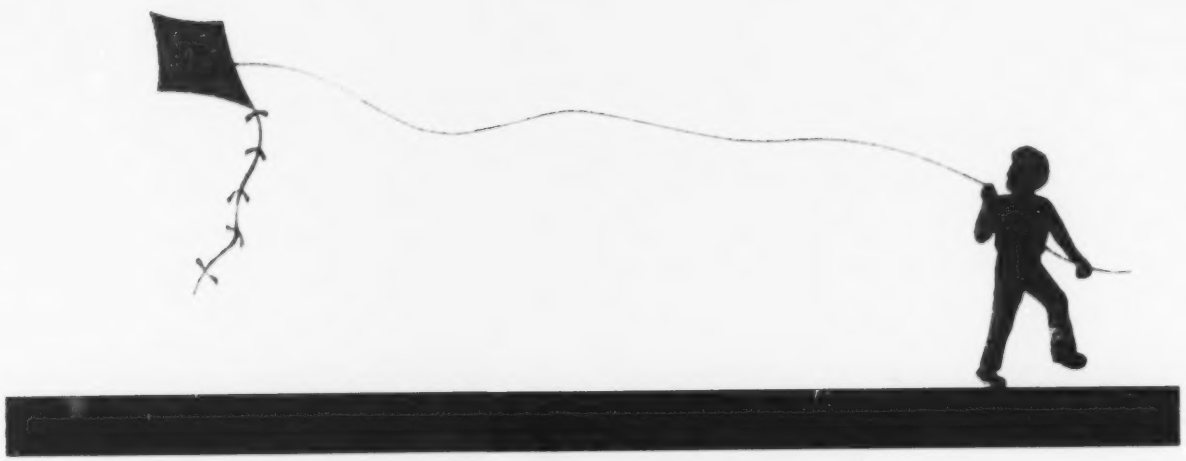

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BOOKLET MAY BE REPRODUCED

Information contained in this booklet is meant to supplement the advice of a physician or other health professional. Ask your physician about your child's specific needs.

Credits

Thank you to the many families, physicians and health professionals who shared their expertise and insight for development of the guidelines. Also, thanks to the members of the Ad Hoc Advisory Task Force for their assistance in planning and developing the guidelines.

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INTRODUCTION

These guidelines are written for families and health professionals. They may also be used by anyone who cares for a child with diabetes including teachers, school personnel, friends, and relatives. Readers may find different sections of the booklet useful at various times during the child's development.

The primary purpose of the guidelines is to help families coordinate the health care that may be needed by a child who has Type I diabetes. This information may help families determine which services are needed for the optimal growth and development of their child. To do this, families need to understand the health care system and how to use it effectively.

Diabetes has an impact on the whole family. The family needs to be the primary manager or coordinator of the child's health care. Health care services are a resource for families. They provide information and care for children with special health care needs. Families who are actively involved in coordinating their child's care assure their child better health care. This is because informed, involved families can promote communication with and between health professionals. Involved families also understand how the health care plan meets the needs of their child better than anyone else. These parents know when the plan is not working well for their child. They can identify unmet needs or duplication of services. Parents are encouraged to actively participate with health care providers to assure that their child's needs are met.

The challenge to health professionals is to serve families appropriately and effectively by providing **family-centered care***. This can be accomplished by providing health care within the context of each family's values, ideals, culture, and lifestyle. The family also benefits from **community-based** services, as close to the child's home as possible.

Individual children's needs vary. These guidelines list the most common health care needs of a child with diabetes. ***Ask your doctor how your child's health care needs are different from those listed here.***

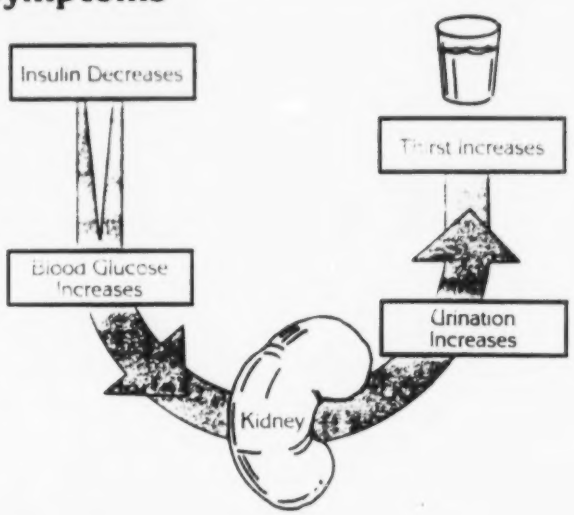
*Words that you see printed in dark type are explained in the Glossary that appears later in this booklet. Turn to the Glossary whenever you are not sure of the meaning of a word in dark type.

GENERAL INFORMATION

What is diabetes mellitus, Type I?

Diabetes affects approximately 1 of every 500 children. It is a **chronic disease**. This means that diabetes goes on forever. With Type I diabetes, the body does not produce enough of a substance called **insulin**. Insulin is produced in an organ of the body called the **pancreas**. Insulin is needed to get glucose (sugar) from food into all the cells of the body. When a person doesn't produce enough insulin, the cells cannot use all of the glucose from the food that is eaten. The extra glucose then builds up in the blood. When too much glucose builds up, the kidneys take the extra glucose from the blood. The kidneys then get rid of some of the extra glucose by putting it out of the body in the urine. The kidneys produce extra urine to do this. This causes the child to **urinate** more often. Frequent urination causes the body to lose a lot of water, which makes the child unusually thirsty.

Diabetes Symptoms



What are the symptoms of diabetes?

These are the symptoms of diabetes:

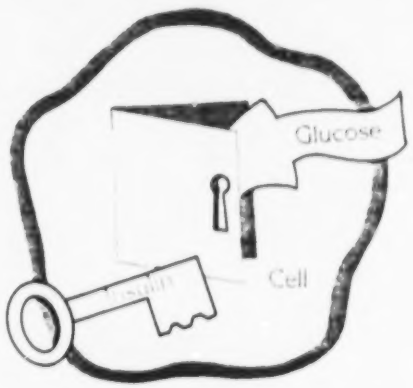
- Frequent urination (frequent need to empty the bladder)
- Unusual thirst
- Extreme hunger

- Sudden weight loss
- Weakness and fatigue or tiredness
- Nausea and vomiting

What causes Type I diabetes?

Although no one is certain, it appears that two factors need to be present to cause diabetes. First, there needs to be a **genetic predisposition** to develop diabetes. Having a genetic predisposition means that a person inherits a tendency to develop diabetes. Second, there needs to be a trigger to cause the condition. Often a virus is the trigger. This combination of genetic predisposition and a trigger causes diabetes. You cannot catch diabetes. It is no one's fault when a person develops diabetes.

Insulin is the key that lets glucose into the cells.



How is my child affected by diabetes?

Because they don't produce insulin, diabetic children can't break glucose down to get the energy it contains. If a child does not receive insulin, the body will try hard to get energy from something else. The body begins to break down fats to replace the energy that it should be getting from glucose. The by-products **(ketones)** from breaking down these fats produce a severe condition called **ketoacidosis**. Stress or illness can cause ketoacidosis. A person who has ketoacidosis will feel nauseated and may vomit. You should always give your child insulin, even when your child is sick, to prevent ketoacidosis. A person with ketoacidosis needs *immediate* medical treatment.

Will my child develop other physical problems?

Other physical problems may be minimized when diabetes is kept in control. Changes do occur in many people after having diabetes for many years. These changes include vision problems, changes in touch sensation, and changes in blood vessels. With poor diabetes control, the problems can occur sooner and cause kidney failure, blindness, heart disease or stroke. A doctor should check your child regularly for early signs of these problems. Good diabetes control can delay or prevent these complications.

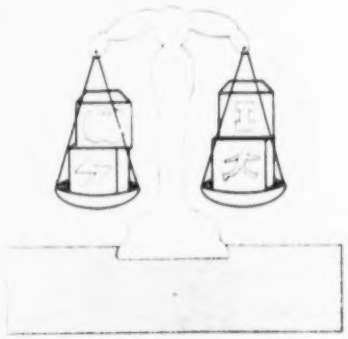
Do the effects of diabetes vary?

It is thought that most people with Type I diabetes produce little, if any, insulin. Diabetes can cause short- and long-term complications. Families may be able to prevent most complications by keeping the child's diabetes in control. Diabetes control is a balance of diet and stress management combined with insulin and exercise. Control of your child's diabetes will vary at different ages and during times of illness, and because of individual differences.

The effects of diabetes on children vary because of several factors:

- The amount of insulin produced by the body varies
- The response to insulin in the body varies
- The activity of the child varies
- Psychological and social stresses vary
- The child's response to stress varies

Diabetes control is a balance.



HEALTH CARE

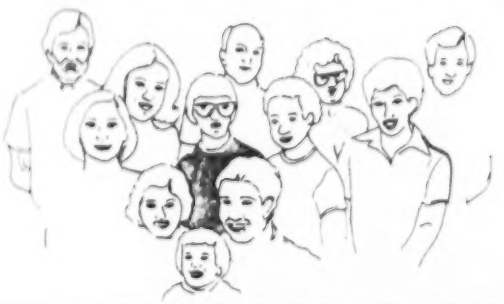
Many health care providers use the **Family-Centered Health Care Team** approach to treat a child or youth with diabetes. Using this approach, health professionals and the family decide together which treatments are best for the child. The family coordinates or arranges the child's health care. This way, the family takes an active part in planning health care for the child.

These are goals of treatment for the child with diabetes:

- Normal growth and development of the child
- Prevention of complications of diabetes
- Nearly normal **blood glucose** levels
- Normal lifestyle including participation in the usual activities of childhood and adolescence
- Knowledge of diabetes and good self-care skills

These goals can be accomplished through the efforts of the family and health professional team by taking these steps:

- Health care team management
- Educating the child and family about diabetes
- Monitoring the child's overall health and watching for complications
- Providing a balanced and nutritious diet
- Giving appropriate insulin dosages at the correct times
- Monitoring blood glucose levels
- Balancing diet and stress management with insulin and exercise
- Encouraging and helping the child develop self-care abilities
- Providing a consistent and predictable home life to make controlling diabetes easier



The Health Care Team

Members of the health care team for the child or youth with diabetes include the following people:

The Child or Teenager and their Family - The most important members of the team!

- Provide personal and family health history
- Observe and describe symptoms and problems
- Record blood glucose levels to help determine insulin needs
- Work with the rest of the health team to develop a care plan
- Communicate with the rest of the health care team about changes in the child's condition and the effectiveness of treatment

Family Physician or Pediatrician - The primary doctor

- Performs well-child examinations, including hearing and vision tests
- Gives immunizations
- Monitors the child's growth and development
- Checks **blood glucose** levels
- Performs **urinalysis** or urine testing
- May monitor **glycosylated hemoglobin** or **Hb A1c** for overall diabetes control
- Treats illnesses
- Prescribes medications
- Communicates with parents, teachers, and other professionals who are involved in the child's care
- Monitors the family's strengths, emotional well-being, and stress level

Pediatric Endocrinologist - Children's physician for disorders of the pancreas and other glands of secretion

- Diagnoses diabetes
- Prescribes and adjusts insulin initially
- Provides family diabetes education
- Monitors diabetes control
- Gives examinations to monitor for complications of diabetes
- Recommends treatment to the family and primary physician

Ophthalmologist - Eye doctor

- Examines the internal structures of the eyes
- Monitors for visual problems related to diabetes

Diabetes Nurse Educator · Registered nurse specializing in diabetes

- Discusses insulin types and helps the child and family adjust insulin dosages
- Provides information about supplies such as glucose meters and jet injectors
- Suggests how to balance insulin and exercise with diet and stress management
- Teaches families how to manage diabetes

Diabetes Nutrition Educator · Registered dietitian specializing in diabetes

- Determines adequacy and quality of the child's diet
- Sets guidelines for calorie needs for the child's optimum growth and development
- Suggests how to balance diet with exercise
- Develops a nutrition care plan

Physical or Exercise Therapist

- Plans an exercise program for the child or youth
- Monitors the child's physical abilities and stamina

School Nurse or County Public Health Nurse

- Makes an Individual Health Plan (IHP) for the child
- Helps the child and family coordinate the child's health care needs in school and school-related activities
- Helps the child and family communicate health information to teachers and other appropriate school personnel
- Helps teachers provide an appropriate learning environment for the child
- Performs special health care procedures and gives medications in school

Social Worker or Family Counselor

- Helps the family learn to balance family life with the child's care
- Helps the family deal with parenting and behavior concerns.
- Provides referrals to community resources

Periodic Health Care

The main goal of health care is to promote normal growth and development of the child and to prevent complications. The family has an important role in accomplishing this goal. It can provide structure for the child which makes managing diabetes easier. Consistency and planning ahead help the family live well with diabetes. Periodic health care visits can also help the family meet the child's health care goals.

Regular health care visits are important to your child's well-being. These visits are necessary to check your child's growth and development as well as the child's diabetes. The schedule of regular visits will vary with the age of the child or adolescent. Children with diabetes are individuals, and their needs will vary. ***Ask your doctor if your child's health care needs are different from those listed here.***

- Visit your doctor(s) four times each year or as recommended:
  - Three visits with your regular doctor
  - One visit with a specialist — pediatric endocrinologist
- Your visit with the doctor will probably include the following:
  - Immunizations
  - Height and weight measured and graphed
  - Blood pressure checked
  - Periodic hearing and vision screening
  - Discussion of the child's development since the last visit
  - **Blood glucose level** test and review of blood glucose levels since the last visit
  - **Glycosylated hemoglobin** test or **Hb A1c** test (every 3 to 6 months) This test shows overall blood glucose control.
  - **Triglyceride blood level** test (every 2 years)
  - Routine urine test (every year) for protein
  - Physical examination including looking at bare feet
  - Discussion of insulin types, dosages, and dosage times
  - Discussion of your questions and concerns

- Meet with a diabetes nutrition educator when you first learn that your child has diabetes. Continue to meet with the nutritionist yearly or more often during active growth.
- Meet with a diabetes nurse educator also at the time of diagnosis. Then, 3 to 12 months later, attend a class or meet with an educator for more instruction. Arrange to meet with an educator at least once each year.
- Meet with a social worker or family counselor at the time of diagnosis and whenever you have concerns about coping with diabetes.

When should I seek medical care for my child?

If your child has any of the following symptoms, contact your physician. If blood glucose is frequently high or low, the physician needs to re-evaluate insulin needs. Infections can make diabetes control difficult.

These symptoms need medical attention between regular visits:

- Signs of infection
  - wound with redness, swelling, or drainage
  - pain or tenderness
  - fever
  - bladder or kidney infection
  - burning sensation when urinating
  - frequent urination
  - tenderness in the lower back or sides
  - cloudy or pink **urine**
- Yeast infection
  - white patches in mouth
  - white **vaginal** discharge and vaginal itching in women
- Difficulty managing diabetes
  - high **blood glucose** level often above 200 **milligrams per deciliter (mg/dl)**
  - low blood glucose level and frequent **insulin reactions**
- Illness and other childhood medical problems

These symptoms need *immediate* medical attention:

- Repeated vomiting
- Abdominal pain
- Fruity odor to breath (**ketones** make the breath smell fruity)
- **Ketones** in urine
- Difficulty breathing
- Changes in alertness
- **Dehydration** (signs include sunken eyes, dry mouth and lips)
- **Insulin reactions** (low blood sugar) that do not get better after taking food or sugar.

If you cannot reach the doctor, go to the nearest hospital emergency room. ***Ketoacidosis*** *can quickly become life-threatening.*

This table compares the signs and symptoms of **ketoacidosis (high blood sugar)** with the signs and symptoms of **insulin reaction (low blood sugar)**:

	High Blood Sugar	Low Blood Sugar
Onset	Gradual	Sudden
Illness prior to onset	Yes, frequently	No
Fever	Sometimes	No
Appearance	Extremely ill	Very weak
Skin	Dry and flushed	Moist and pale
Mouth	Dry	Wet
Thirst	Intense	Absent
Hunger	Absent	May be present
Vomiting	Common	Rare
Fruity breath	Yes	No
Blood glucose	High - usually more than 200 mg/dl	Low - less than 70 mg/dl
Adapted from Merck Manual, 1982. Merck & Co., Rahway, NJ.		

Record Keeping

Record Keeping is an important part of managing diabetes. Your doctor or diabetes educator can give you a record booklet for diabetes. The booklet will have places to record insulin dosages and **blood glucose levels.**

Information to record may include the following:

- Name, addresses and phone numbers of health team members
- Immunizations
- Appointment dates
- Daily care plans — diet, insulin, and activity
- Blood glucose records
- Insulin reactions
- Illnesses

A parent may find it useful to audiotape the doctor's instructions so that the spouse can hear the doctor's comments too. The family can also replay the tape later to review the instructions.

THE CHILD'S NEEDS

Infants and Toddlers with Diabetes — Ages 0 to 2

Health Care

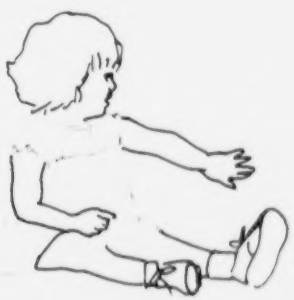
- Children who develop diabetes can be treated as **outpatients** (kept at home, not in a hospital). Happily, hospitalization is not as frequent as it used to be. Insulin needs are easier to adjust when the child is home and has the usual foods and activities.
- Children in this age group are growing fast and may need to have their insulin dosages changed frequently.
- Infants and toddlers need to have their blood glucose checked several times each day. They may also need to have their insulin dosage split and given at different times. Follow your doctor's recommendation about these procedures.
- Remember that your child needs the same well-baby checkups and immunizations that all children need.

Development

- Food and eating may be a problem for the infant or toddler with diabetes. Family members need to recognize signs of low blood glucose. Children with low blood glucose may have a sudden change in behavior. If your child's behavior seems unusual, check his or her blood glucose level.
- Tell the infant or toddler that the insulin injections keep him or her well, rather than make him or her better. Also, praise the child for holding still for injections and finger sticks rather than dwelling on negative behavior. Toddlers can be involved in their care by handing parents cotton balls and other supplies.
- Provide a safe environment that allows your child to play with the least restriction. Provide toys and activities that are right for your child's age.
- All children are better able to manage life if they feel good about themselves. It is important to begin building self-esteem early by praising your infant or toddler often.

Day Care

- Choose a day care provider who is willing to learn about caring for a child with diabetes. Be sure you feel confident in the provider's ability to understand your instructions and handle emergencies.
- Be sure the day care provider knows about signs of insulin reaction and how to treat it. Make an emergency plan with the day care provider and review your plan regularly. Be sure to include phone numbers for the following:
  - Several family members, including your number at work
  - Your child's doctor
  - Your hospital emergency room



Preschool Children with Diabetes — Ages 3 to 5

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Children who develop diabetes are usually treated as **outpatients** (kept at home, not in a hospital). Happily, hospitalization is not as frequent as it used to be. Insulin needs are easier to adjust when the child is home and has the usual foods and activities.
- Preschool children need to have their blood glucose checked several times each day. They may also need to have their insulin dosage split and given at different times. Follow your doctor's recommendation about these procedures.
- Preschool children may resist eating at times. This is not usually a problem for most children, but for children with diabetes, it can be a major concern. Discuss eating problems with your physician or diabetes educator.

Development

- Provide your child will simple information about diabetes.
- Tell the child that the insulin injections keep him or her well, rather than make him or her better. Also, praise the child for holding still for injections and finger sticks rather than dwelling on negative behavior.
- Begin to alert your child to symptoms of low blood sugar. Parents still will need to find behavior clues to insulin reactions.
- Some children resist eating at this age. It may help if you don't get in a power struggle with your child over eating. Offer a variety of foods, but do not force the child to eat.
- Expect the same behavior from the child with diabetes as from other children. Set appropriate limits on your child's behavior. Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, all children have the same needs for love and discipline.
- All children are better able to manage life if they feel good about themselves. It is important to begin building your child's self-esteem early by praising your child often.
- Provide your child with opportunities to do the following:
  - Learn the names of the equipment used for diabetes care
  - Start to learn about diabetes testing by wiping finger, pushing buttons and other simple activities
  - Play with other children of the same age
  - Learn to start and complete activities when playing
  - Have a balance between structured activities and free time to play
  - Succeed, so the child gains self-confidence

School

- At the beginning of each school year, meet with the school nurse and your child's teachers. Keep them informed of changes in your child's condition and treatment. Parents can participate in making their child's Individual Health Plan. For a list of specific topics to discuss with school staff, read the information on schools in the Family Support and Services section of this booklet.

School-Age Children with Diabetes — Ages 6 to 12

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Children who develop diabetes are usually treated as **outpatients** (kept at home, not in a hospital). Happily, hospitalization is not as frequent as it used to be. Insulin needs are easier to adjust when the child is home and has the usual foods and activities.
- Attend an educational class on diabetes with your child or meet with a diabetes educator at least twice each year.
- Meet with a nutritionist to review your child's diet plan at least once each year; also at times of changes in activities and whenever diet is a concern.

Development

- Consider having your child attend camp. In Minnesota, Camp Needlepoint and Camp Day Point offer recreational activities and also teach children to manage their diabetes. What they learn at camp will help children manage diabetes throughout their lives.
- School-age children understand factual information about diabetes. Give them specific information about their condition. Attending family diabetes education programs can provide children and parents accurate, specific information that school age children need.
- All children are better able to manage life if they feel good about themselves. It is important to begin building your child's self-esteem early by praising your child often.
- Encourage your child to do blood glucose testing and be in charge of taking their own insulin, once you have checked the dosage. Mastering these skills will give your child self-confidence and a feeling of accomplishment.
- As the child's knowledge and skills develop, allow your child increasing control over his or her diet and medication with supervision.
- Children of this age group are usually quite active. They may need limits on their television time. Regular activity is especially important for children with diabetes.

- Find or start a support group for children with diabetes. Support groups offer recreation and give the child a chance to make friends with other children who have similar concerns.
- Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

School

- Meet with your child's teachers and school nurse at the beginning of each year. Keep them informed of changes in your child's condition and treatment. Parents can also participate in making their child's Individual Health Plan. For a list of specific topics to discuss with school staff, see the information about schools in the Family Support and Services section of this booklet.
- Encourage your child to take part in school sports and social activities.

Adolescents with Diabetes — Ages 13 to 17

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- If the teenager has had diabetes for more than 5 years, arrange for an eye exam by an ophthalmologist each year.
- Meet with a nutritionist to make adjustments in the teen's diet during times of rapid growth. Meet with the nutritionist at least once each year. Diabetes may be more difficult to control during early adolescence because of hormone changes.
- Learn to adjust the insulin dosage if you or the teen observe a pattern of high or low blood glucose. Change dosage slowly, only one type of insulin at a time. It may take 2 to 3 days to notice a change after insulin is adjusted. Insulin dosage adjustments may also be necessary during times of rapid growth.

Development

- Find or start a support group for teenagers with diabetes. Support groups offer recreation and give the teenager a chance to make friends with other teens who have similar concerns.
- Independence within limits is necessary for teenagers to develop responsible behavior. Encourage the teen to decide about insulin adjustments and diet. Responsible behavior will usually follow independence, if the teen understands the benefits or consequences of his or her actions. Teenagers can usually develop their own schedule and select groceries.
- Peers become increasingly important to teenagers. Young people with high self-esteem can resist peer pressure. They will also be less concerned about being different from their friends.
- Diabetes may delay growth and physical maturation if blood glucose control is not optimal. Being slow to grow and develop may cause a teenager some unhappiness.
- Drinking alcohol can cause problems in trying to control diabetes. Alcohol can affect **blood glucose levels.** It can also make recognizing an **insulin reaction** more difficult.
- Smoking is unhealthy for everyone. In people with diabetes it can also cause disease of the blood vessels.
- Young people need to understand how diabetes will affect their sexual and reproductive life. They may need to be encouraged to ask questions. Booklets about sexuality are listed in the section on Resources for Children with Diabetes at the end of this booklet. Discuss contraception with the teen. If you are uncomfortable, encourage the young person to discuss sexuality with physician, nurse, or family therapist. Women who have diabetes need to carefully plan their pregnancies. Serious birth defects or death of the baby can occur if a pregnant woman has poorly controlled diabetes.
- To receive a driver's license in Minnesota, people with diabetes must have their physician sign that their diabetes is in good control. Discuss driving concerns with your physician.

School

- If a teenager has problems managing diabetes at school, parents can arrange a conference with the involved school staff.The meeting may include the teen, physician, school nurse, physical education teacher and other teachers.
- Adolescents usually resist informing others of their condition and needs. Therefore, parents may need to be advocates for the teenager at school more than when the teen was younger.
- Encourage the youth to be involved in after school activities.
- Many teens need encouragement to begin planning for their future education and career during their high school years. In Minnesota, if the teenager has a chronic health condition that could affect career choices, vocational counseling is offered at age 14.

Young Adults with Diabetes — Ages 18 to 21

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- When the young adult moves away from home or gets a job, find out if the current health insurance coverage continues. Some insurance policies will cover young adults only if they attend school as a full-time student. Discuss health insurance needs with your insurance company, local county human services worker, public health nurse, or your physician.
- If the young adult has had diabetes 5 or more years, arrange eye exams with an ophthalmologist annually.
- Sexually active young adults should meet with a physician to plan for contraception. Women with diabetes need to carefully plan their pregnancies. Special care is needed before and during pregnancy.

Development

- Young adults focus on life goals, education, and career as they develop their independence. Diabetes may influence career choices. A young adult unsure of his or her goals may want to seek assistance in career planning.
- Drinking alcohol can cause problems in trying to control diabetes. Alcohol can affect **blood glucose levels.** It can also make recognizing an **insulin reaction** more difficult.
- Smoking is unhealthy for everyone. In people with diabetes it can also cause disease of the blood vessels.
- Young adults need to understand how diabetes will affect their sexual and reproductive life. Booklets about sexuality are listed in the section on Resources for Children with Diabetes at the end of this booklet.
- To maintain a driver's license in Minnesota, the young adult must keep diabetes in control. Physicians need to sign a statement about this for the individual.

School

- Young adults who go away to school should plan for emergencies or illnesses. They can also plan to have routine follow-up visits with their physicians when they are home on vacation. Some colleges and educational institutions have medical resources available. Request information about medical resources when finding out about a school.

FAMILY SUPPORT AND SERVICES

Advocacy

Parents of children with chronic conditions need to learn to be advocates. A lot of advocacy is just teaching people about your child's condition and needs. Parents understand their child's needs better than anyone else. Parents have a lifelong relationship with their child. However, health professionals come and go over time. Advocacy also means having a positive attitude toward diabetes without shame or embarrassment.

Another part of advocacy is being persistent in seeking a service or treatment that your child needs. If one person says you do not qualify for the service or the child does not need a treatment, ask another person. Continue to tell health providers about your concerns until you are satisfied with their answers.

Finally, you may need to remind people who are treating your child about treating the whole child. Some health care providers will focus on one goal for your child's treatment, but may forget how that goal affects other areas of the child's life. An example of this is trying to fit treatments into your child's school schedule. You may need to discuss your child's treatment plan with school staff to best meet both treatment and school needs. If your treatment or insulin plan is not effective in preventing problems, work with health care providers to develop an alternative plan that will work better.

Schools

Each fall, meet with teachers and the school nurse to discuss the following:

- Your child's Individual Health Plan (IHP)
- A plan to keep staff and family informed
- Symptoms of an insulin reaction
- Treatment for insulin reactions
  - Extra snacks
  - Use of glucose or glucagon
  - When to notify parents
- Blood glucose monitoring
- Nutrition needs
  - Lunch
  - Extra snacks
  - Foods at parties
- Appropriate school schedule
- Coordinating food with exercise
- Your child's needs on the bus, during field trips and other activities.

Human Services

When a family member has a **chronic condition**, families may feel financially and emotionally strained. The child's behavior can affect the success of a diabetes management plan. County social service departments have information about financial resources to help with the cost of medical care. Their staff can assist families with emotional and parenting concerns. Local mental health centers, private licensed psychologists, and social workers can also help families with problems that may arise. Your child's physician can refer you to these local services.

Family Support Groups and Networks

Sometimes it is helpful for parents to talk to other parents of children with diabetes. Other parents who have a child with the same condition can give encouragement and support with an understanding that comes from experience. You can find informal networks of parents through your doctor, diabetes educator, the American Diabetes Association of Minnesota, or classes on diabetes. The Association for the Care of Children's Health publishes a *Parent Resource Directory* with names and addresses of families of children with special health care needs

with similar concerns. Support groups may also be available for families and siblings. Family-to-family support can often give families insight into options in managing diabetes. Discussions may also help resolve the stress and emotional concerns that many families have. Check with your diabetes educator or hospital to find out if there is a group in your area. If not, you may be able to start one with the help of a diabetes educator.

Recreation

With planning, your child can participate in all the usual childhood activities. You should inform coaches or other group leaders of the special problems and needs that a child with diabetes might have.

Exercise is a very important part of keeping diabetes in control. Low resistance-high movement exercise such as swimming and cycling are good for a person with diabetes. Children are usually very active without much encouragement until adolescence. If the youth is not very active during the teen years, a physician, physical therapist, or diabetes nurse educator can help plan an exercise program.

Before traveling, list the equipment and medications that you need to bring along. Bring enough insulin and supplies for the entire trip and keep them with you. Don't check medicine, snacks, glucose, or supplies with baggage. Be especially well prepared when traveling to areas where health care is not readily available. If your child is traveling to another country, contact the International Association for Medical Assistance for Travellers (IAMAT) for help in locating an English speaking doctor in foreign countries. For more information, see the material on organizations in the section on Resources for Children with Special Health Care Needs at the end of this booklet.

Respite Care

Finding someone to watch your child when you go out can be complicated when you have a child diabetes. You might feel uncomfortable leaving your child with babysitters who may not understand your child's condition. You could teach a relative how to spot symptoms of insulin reactions and what to do if one occurs. As your child gets older, he or she will be increasingly responsible for his or her own diabetes care and can help in teaching others about diabetes. Contact the American Diabetes Association to locate teenagers with diabetes who can care for your child. The association is listed in the information on organizations in the section on Resources for Children with Diabetes.

Safety

Children with diabetes should always carry some food to raise **blood glucose level**, in case they have an **insulin reaction**. Your doctor, nutrition educator, or nurse educator can help you decide what kind of glucose product or food the child should carry along.

Your child should wear an identification bracelet or necklace with the word Diabetes engraved on it. If your child has an insulin reaction and cannot tell others, the bracelet will alert them to your child's condition.

Siblings

The brothers and sisters of a child with special health care needs have concerns other children don't have. They have many adjustments to make. They may have mixed feelings about their responsibility to the child with special health needs. They may feel guilty about being normal. They also may be angry that they do not receive as much "attention" as the child with special needs does.

Parents can help siblings adjust in several ways. Parents can give each of their children individual time without interruption. They can also assure their children who don't have diabetes that their feelings are okay. Relationships between siblings should stress friendship rather than caregiving. The siblings of a child with diabetes may benefit from the support of a person outside the immediate family. This may be a relative or a trusted friend. Other resource people may include school teachers, coaches, counselors, and spiritual leaders. With support, children can grow through the experience of having a sibling with special health care needs.

GLOSSARY

Autoimmunity - A process in which the body's immune system attacks a part of the body. Cells that produce insulin may be destroyed by autoimmunity.

Beta Cells - Small groups of cells in the pancreas that produce insulin.

Blood Glucose Level - A measurement of the amount of sugar in the blood, taken from a blood sample. The blood is usually obtained from a finger-stick.

Blood Glucose Monitoring - Checking the level of sugar in the blood several times each day by placing a drop of blood on a test strip. The pad on the test strip changes color to indicate the blood glucose level.

Cells - The building blocks of the body which use glucose for energy.

Chronic Condition/Disease - A condition that affects a person for a long time.

Community-Based Care - Services available as close to home as possible; within the community as defined by the family; includes the local doctor, clinic, outreach specialty clinics, the public health nurse, the school, public and private agencies

Culturally-Sensitive - Care that is responsive to the values, beliefs, social norms, and behaviors of the individuals or populations being served; recognition of the values of different population groups. (From New England SERVE)

Deciliter - A measurement of one-tenth of a liter; about one-tenth of a quart.

Dehydration - Excessive water loss from the body.

Developmental Delay - When children have not begun certain activities by the age that most children can perform the same activity. They may be slow to learn to talk, walk, feed and dress themselves, read, write, or other activities.

Diabetes Mellitus, Type 1 - Insulin-dependent diabetes; formerly called juvenile-onset diabetes. Type 1 always requires insulin therapy.

Family-Centered Care - Health care that recognizes the family as the constant in the child's life, and that is flexible, accessible, and responsive to family needs.

Family-Centered Health Care Team - A group of health professionals who work together with the family to provide the best care for each child with special health care needs.

Genetic Predisposition - An inherited tendency to develop a condition.

Glucagon - A hormone produced by the pancreas to raise blood glucose levels. Glucagon can also be given by injection.

Glucose - A common form of sugar that is produced when food is digested.

Glycosylated Hemoglobin - Hb A1c. A blood test that gives a good indication of overall diabetes control over the past months.

Hyperglycemia - High blood glucose.

Hypoglycemia - Low blood glucose.

Individual Education Plan (IEP) - A plan for children receiving special education services; to meet a child's unique learning needs with a detailed plan.

Individual Family Service Plan (IFSP) - A plan to meet the unique needs of children with special needs ages 0 to 3 and their families; developed by a multi-disciplinary team including the parents.

Inpatient - A person who is a staying in a hospital for treatment.

Insulin - A hormone produced by the pancreas to make glucose available to cells.

Insulin Dependent Diabetes Mellitus - IDDM or Type I diabetes.

Insulin Reaction - Low blood glucose, also called insulin shock and hypoglycemia.

Ketoacidosis - A condition where blood glucose and ketone levels are very high.

Ketones - A waste product of the body that is produced when fat is burned for energy.

Milligram - A measurement of one-thousandth of a gram in weight; it is abbreviated mg.

Multidisciplinary Team - A group of professionals from different fields who work together to give specialized services to the family.

Nephropathy - A complication of diabetes in which the kidneys do not filter wastes from the blood.

Neuropathy - A complication of diabetes in which nerves are damaged and cause numbness or tingling.

Outpatient - A person who goes to a hospital or clinic for treatment for a short time during the day.

Pancreas - A gland in the abdomen that produces insulin.

Pediatric Endocrinologist - A doctor for children with diabetes or other gland problems.

Respite Care - Care given by people outside the immediate family to give family members a rest from caregiving responsibilities.

Retinopathy - A complication of diabetes in which the blood vessels in the back of the eye are damaged.

Triglyceride Blood Test - The level of fat in the blood.

Urinalysis/Urine Testing - Checking the chemical content of urine. Testing may be for sugar, ketones, bacteria, and other components of urine.

Urine - The liquid waste product that is filtered by the kidneys and stored in the bladder.

Vaginal - Pertaining to the vagina; the female passageway to the uterus and the birth canal.

RESOURCES

for Children with Diabetes

Organizations

American Association of Diabetes Educators (AADE)
Minneapolis-St.Paul Diabetes Educators (Chapter of AADE)
Diabetes Nurse Educator
Box 603 University Hospital
Minneapolis, MN 55455

The AADE of Mpls/St. Paul chapter provides a directory of diabetes educators throughout Minnesota. This directory lists diabetes educators by location. Diabetes educators offer information about diet, insulin, and supplies such as glucose meters. They also provide emotional support to families. To receive a copy of *Minnesota Diabetes Educators*, write to the above address.

American Diabetes Association (ADA)
Diabetes Information Service Center
1660 Duke Street
Alexandria, VA 22314
(800) ADA-DISC

The American Diabetes Association publishes a catalog of information available through its service center. Several of their publications are noted in the resource sections. Many of the pamphlets are free. Phone or write to find out about the cost of books or other materials.

American Diabetes Association (ADA) of Minnesota
715 Florida Avenue South, Suite 307
Golden Valley, MN 55426
593-5333

The ADA of Minnesota offers several services to children with diabetes. Some of these include the following:

- Camp Needlepoint: a residential camp for children ages 8 to 16 who have diabetes.
- Camp Day Point: a day camp for children ages 6 to 9 who have diabetes.
- Annual Halloween party.
- *Action*, a newsletter for people of all ages.
- Referrals to support groups and other agencies.
- All A.D.A. publications are available through this office.

International Diabetes Center (IDC)
5000 West 39th Street
St. Louis Park, MN 55416
(612) 927-3393

The IDC offers an intensive, 5-day education program to help people with diabetes and their families learn to manage diabetes. They teach nutrition and meal planning, the newest ideas for treating diabetes, what to do during illness, stress management, exercise, how to plan for special occasions, and more.

Juvenile Diabetes Foundation International (JDF)
432 Park Avenue South
New York, NY 10016
(800) 223-1138

The JDF is an organization that raises money for diabetes research. It also has informational pamphlets available free to families and health professionals. Several of its pamphlets are listed in the resource sections.

National Diabetes Information Clearinghouse (NDIC)
Box NDIC
Bethesda, MD 20892
(301) 468-2162

NDIC has materials about diabetes for families and health professionals. It also has two lists of written materials: *Diabetes in Children and Young People; Educational Materials for and about Young People with Diabetes.*

Books, Pamphlets, and Videos for Children and Families

Many of the books listed here are available through the Minnesota public library system. Books that are not available at the local library can be borrowed from any other public library in Minnesota.

American Association of Diabetes Educators of Minnesota:

Minnesota Diabetes Educators. 1988. This is a directory of diabetes educators throughout Minnesota.

American Diabetes Association Publications:

Children: Diabetes and You. 1987. 16-page booklet
Parents: Diabetes and You. 1987. 36-page booklet
Teens: Diabetes and You. 1988. 46-page booklet
This series of booklets has information about diabetes care. The children's booklet is written for school-age children. The teen booklet gives basic information and also describes ways that teens can learn to fit diabetes into their lives. Concerns such as school, sports, dating, drinking, smoking and careers are discussed.

Children with Diabetes. 1986. 76-page book.
This book offers specific information about managing children's diabetic care. Chapters cover treatment, meal planning, exercise, testing, medical concerns, and concerns that develop at different life stages.

Diabetes Forecast. A monthly magazine for families with a member who has diabetes.

Pamphlets:
Anger: A Message to the Adolescent with Diabetes
Diabetes: Facts You Need to Know
Nutrition for Children with Diabetes
Publications Catalog
Your Child Has Diabetes: What You Should Know

International Diabetes Center Publications:

Learning to Live WELL with Diabetes. 1987. 394 pages.
This comprehensive book gives detailed information on managing diabetes. It has a chapter to be read by or to a child with diabetes. Topics include testing, skills, exercise, nutrition, motivation, and emotional adjustment.

Easy-to-Read Series of seventeen booklets about diabetes written at third-grade reading level. Subjects include: diabetes type I, giving insulin, healthy eating, blood sugar testing, urine testing, brief illnesses.

Living Well with Diabetes. Magazine for people with diabetes.

Prevention and Treatment of Five Complications of Diabetes. A guide for patients that contains an introduction to day-to-day management of diabetes.

Teenagers: Sexuality and Diabetes. A 6-page paper for teenagers with diabetes and their parents.

Juvenile Diabetes Foundation Publications: (Series of pamphlets)

A Guide for the Diabetic Woman Having Children
The Search for a Cure
Self Blood Glucose Monitoring
What You Should Know about Insulin
What You Should Know about Juvenile (Insulin-Dependent) Diabetes
Your Baby Has Diabetes
Your Child Has Diabetes

U.S. Department of Health and Human Services. 1989. *The Diabetes Dictionary.* NIH Publication #89-3016. 65-pages. Available from the National Diabetes Information Clearinghouse.

Articles, Books, and Pamphlets for Health Professionals

American Association of Diabetes Educators (AADE) Publications:

The Diabetes Educator. Periodical.

Minnesota Diabetes Educators. Statewide directory of diabetes educators; for the state affiliate of AADE.

American Diabetes Association Publications:

Clinical Diabetes. Periodical.

Curriculum for Youth Education. 1983. Booklet.

Diabetes Care. Periodical.

Diabetes Spectrum. Bimonthly magazine for health professionals.

Guidelines for Diabetes Care. Educational guidelines.

Physician's Guide to Insulin-Dependent (Type I) Diabetes. Diagnosis and treatment. 1988.

What the Teacher Should Know about the Student with Diabetes. Information sheet.

A Word to Teachers and School Staff. 1987. Pamphlet.

Fox, Charles, 1986. The Wasted Resource: Helping Young People with Diabetes to Help Each Other. *Diabetes Medicine* 3(5), 475-6.

International Diabetes Center Publications:

Diabetes in Your School or Child Care Center. VHS Videotape, 11 minutes.

Diabetes Youth Curriculum: A Toolbox for Educators. 1988. This is part 1 of the 2-volume set. 130-page manual.

Resource and Activity Guide: The Toolbox. 1988. This is part 2 of the 2-volume set. Three-ring binder with 100 activities.

Quality Audio-Visual Programs. 1988. Leaflet.

Juvenile Diabetes Foundation International Publications:

Diabetes: Low Blood Sugar Emergencies Information card for teachers and others.

What the Teacher Should Know: Your Student has Diabetes. Leaflet for school staff.

National Diabetes Information Clearinghouse. 1987. *Diabetes in Children and Young People.* Literature search, 44 pages. Bethesda, MD 20205.

Travis, L.B., Brouhard, B.H., & Schreiner, B.J. 1987. *Diabetes Mellitus in Children and Adolescents.* W.B. Saunders. 343 pages.

Specialty Medical Care for Children with Diabetes

Doctors who specialize in the care of children with diabetes are called **pediatric endocrinologists**. Several medical centers in Minnesota have this type of doctor. These doctors can provide specialty care for children with diabetes. Children with diabetes are usually also seen by their regular doctor for well-child care including immunizations.

Children's Hospital of Saint Paul
Endocrinology Clinic
345 Smith Avenue North
St. Paul, MN 55102
(612) 220-6000 or 220-6700

Duluth Clinic
400 East 3rd Street
Duluth, MN 55805
(218) 722-8364

Mayo Clinic
200 1st Street SW
Department of Pediatrics · E9A
Rochester, MN 55905
(507) 284-2511

Park Nicollet Medical Center
International Diabetes Center
5000 West 39th Street
St. Louis Park, MN 55416
(612) 927-3530

Services for Children with Handicaps
Diabetes Clinic · Minnesota Diabetes in Youth Program held in several Minnesota cities including Bemidji, Fergus Falls, Mankato, St. Cloud, Virginia, and Willmar.
Minnesota Department of Health
717 SE Delaware Street, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150
(800) 728-5420

St. Paul Ramsey Medical Center
Department of Pediatrics
640 Jackson Street
St. Paul, MN 55101
(612) 221-3624

University of Minnesota
Pediatric Endocrinology Office - 13-128 P.W.B.
Box 391 - U.M.H.C.
Minneapolis, MN 55455
(612) 624-5409

Please note:
This is a partial list of resources available in Minnesota. We do not endorse any specific organizations or publications. You will need to evaluate the quality of the services and determine if they fit your individual situation.

GENERAL RESOURCES

for Children with Special Health Care Needs

Organizations

Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda MD 20814
(301) 654-6549
ACCH publishes a variety of materials for families and professionals. It offers a newsletter, brochures and booklets, and videos to help families get the most out of the health care system. It also publishes the *Parent Resource Directory*, which contains the names and addresses of parents whose children have special health needs. Parents are listed by area and by their child's condition. The Minnesota chapter is coordinated by a parent. Call or write the national organization to for the current chapter address. Send for the ACCH publications catalog.

County Public Health Nursing Agencies
Minnesota Department of Health
Section of Public Health Nursing
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5468
Each county in Minnesota offers public health nursing services to residents of the county. Some counties offer respite care services or can help families locate respite care. The local agency may also help teach family members and babysitters about the care of the child with special health care needs. Contact your local county, or call the Minnesota Department of Health to locate your local office.

County Social Services
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-6117
County social services offer support and assistance in finding local resources for families such as equipment, respite care, financial aid and intervention services. It also offers care coordination to families. Call your local county for information.

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
(612) 588-0811

Courage Center offers services to children and adults with physical disabilities and speech, hearing and vision impairments and services are also available to family members. It offers adaptive driver education, a Communication Resource Center, camping experiences, a transitional residence program, support programs, physical and occupational therapy, and recreational and athletic activities. *Meeting Ground* is a free bimonthly newsletter written by and for families and health professionals. Call or write for a subscription.

The Early Intervention Project
Minnesota Departments of Health, Education and Human Services
Call your local school district for information.

The Early Intervention Project is a federally mandated program that operates through local interagency committees. Its purpose is to provide services for children from birth to three years of age who have special health care needs or developmental delays. Services may include respite care, public health nursing services, physical therapy, occupational therapy, speech and language therapy, early childhood special education, special equipment, family support activities, and training for parents.

Federation for Children with Special Needs
95 Berkeley Street
Boston, MA 02116
(617) 482-2915

The Federation for Children with Special Needs provides information and resources that focus on improving communication between families and health professionals. It also offers support for parents of children with special needs.

International Association for Medical Assistance to Travellers
IAMAT - USA Membership Office
417 Center Street
Lewiston, NY 14092

IAMAT is an organization that publishes a directory of English-speaking physicians around the world. Fees for visits are set at

low rates. It also offers health information for travelers. The membership and directory are free. Voluntary contributions are encouraged.

MedicAlert Foundation International
Turlock, CA 95381-1009
(800) ID-ALERT

MedicAlert makes identification necklaces and bracelets. The tags list medical information such as diagnosis, medications, and allergies. When someone purchases an ID, MedicAlert keeps a brief medical record on computer, which is updated yearly. Emergency medical personnel can call for more specific information than can be listed on the ID.

Metro Center for Independent Living (MCIL)
1619 Dayton Avenue, Suite 303
St. Paul, MN 55104
(612) 646-8342 (voice or TDD)
(612) 642-2507 (FAX)

MCIL offers transitional programs to promote independent living. Its Used Equipment Referral Service is a network between sellers, buyers, and donators of used equipment. It matches people who need equipment with those who have equipment available. Equipment includes wheelchairs, bathroom equipment, ramps, lifts, vehicles, hospital beds, walkers, prone standers, and more. Cosponsored by MCIL and United Cerebral Palsy of Minnesota.

Minnesota Department of Health
Genetics Unit
717 SE Delaware Street
Box 9441
Minneapolis, MN 55440
(612) 623-5269

Families can call the Genetics Unit to locate resources for genetic counseling for conditions that have a possible hereditary component.

Minnesota Department of Health
Services for Children with Handicaps (SCH)
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free voice or TDD)

SCH offers community-based clinics and services, health education and support programs, and health care financing to families of children with special health care needs. It also offers technical consultation to health professionals. SCH has district offices in Bemidji, Duluth, Fergus Falls, Mankato, Marshall, Minneapolis, Rochester, St. Cloud, and Virginia. Call for more information.

Minnesota State Council on Disability
145 Metro Square Building
7th Place and Jackson Street
St. Paul, MN 55101
(612) 296-6785 (voice or TTY)
(800) 652-9747 (Ask for Minnesota State Council on Disability)

This is an information and referral resource for people with disabilities who live in Minnesota.

National Center for Youth with Disabilities
Adolescent Health Program
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(800) 333-6293

The center offers services to families, youth, and professionals to assist them in developing alternative service systems, which will allow adolescents and young adults to develop to their fullest capacity. It offers a National Resource Library and technical assistance by a network of professionals from many disciplines. The center also fosters the development of community-based services through a national network of federal and state information.

National Information Center for Handicapped Children and Youth (NICHCY)
P.O. Box 1492
Washington, D.C. 20013
(703) 893-6061

NICHCY is a national clearinghouse that provides information about many handicapping conditions. It also offers a list of parent groups throughout the United States and information regarding available services to disabled people.

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
(800) 346-2742

This organization offers a computer information service called ABLE DATA. Call for information.

PACER Center (Parent Advocacy Coalition for Educational Rights)
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966 (voice & TDD)
(800) 53-PACER (toll-free)

PACER Center offers statewide workshops for families of handicapped children. The workshops inform parents of schools' rights and responsibilities to provide free appropriate education programs for children. Specific information is provided about Public Laws 94-142 and 99-457. Written materials are available in English, Spanish, and Hmong languages.

Pathfinder Resources
2324 University Avenue West, Suite 105
St. Paul, MN 55114
(612) 647-6905

Pathfinder works to improve the health and well-being of children with chronic conditions. It offers consultation and technical assistance in networking, education, public policy and financing, and publications.

Pilot Parents of Minnesota
201 Ordean Building
Duluth, MN 55802
(218) 726-4745

Pilot Parents is a parent network that matches families who have children with similar health or developmental conditions. Parents are trained to give information about services and educational programs, and can offer emotional support. Parents are available in most areas of Minnesota including northeastern, northwestern, central, and southeastern Minnesota. Pilot parents hope to have families available in southwestern Minnesota in 1990.

Siblings for Significant Change
105 East 22nd Street
Room 710
New York, NY 10010
(212) 420-0776

This Organization for siblings of disabled people. It offers information and referral services, counseling programs, and community education.

Sibling Information Network
Connecticut's University Affiliated Program
991 Main Street
New Hartford, Connecticut 06108

This is a clearinghouse of information for the siblings and families of disabled people. It offers quarterly newsletters with reviews, resource information, and discussions of family issues.

Wilderness Inquiry
1313 Fifth Street SE
Suite 327A
Minneapolis, MN 55414
(612) 379-3858

Wilderness Inquiry provides challenging wilderness experiences for physically disabled and nondisabled people. The camping trips require interdependence and cooperation. Experiences are available for families with children. Young adults over 18 years old may attend without family members. Some trips are available to teens 13 to 18 years old.

Books, Pamphlets, Videos, and Catalogs of Information

Adams, B. 1979. *Like It Is: Facts and Feelings about Handicaps from Kids Who Know.* Walker & Co., New York, NY. 96 pages. This book is written for school-age children and adolescents.

Aspen Publications. *Infants and Young Children.* 1600 Research Boulevard, Rockville, MD 20850. This journal is for parents and professionals who work with children. For more information phone (800) 638-8437.

Association for the Care of Children's Health, 1987. *Family-Centered Care for Children with Special Health Care Needs.* ACCH, Washington, DC. 74 pages. This book describes family-centered health care. Each chapter has a section that contains specific ideas to "make it happen." The final chapter includes checklists to help evaluate how well health providers are collaborating with families.

Association for the Care of Children's Health, 1988. *Seasons of Caring.* ACCH, Washington, DC. 40-minute videotape. Reveals the strengths and needs of families caring for children with special health care needs. Addresses many issues encountered by parents, teachers, social workers, school administrators, nurses, physicians, and others who care for children with special needs and their families. Another 38-minute video, *Family-Centered Care,* shows the experiences of several families around the country.

The Exceptional Parent. 605 Commonwealth Ave., Boston, MA 02215. This is a consumer magazine for parents of children with chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Exley, H. (editor). 1984. *What It's Like to be Me.* Friendship Press, New York, NY. 127 pages. This book is written and illustrated entirely by disabled children. It's intended for school-age children and those in early adolescence.

Haig, B. and Moynihan, P. 1988. *Whole Parent/Whole Child: A Parent's Guide to Raising the Child with a Chronic Health Condition.* Diabetes Center, Minneapolis. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Harnish, Y. and Leeser, I. 1984. *Patient Care Guides: Practical Information for Public Health Nurses.* National League of Nursing, New York, NY. 211 pages. This book has a section that contains patient care guides for children with chronic conditions. Some of the conditions included are mental retardation, myelodysplasia, neurological handicaps, muscular dystrophy, and cleft lip and palate.

Healy, A. and Lewis-Beck, J. 1987. *Guidelines for Families, Guidelines for Nurses, Guidelines for Physicians, Guidelines for Social Workers, Guidelines for Therapists.* University of Iowa Bookstore, Iowa City, IA 52242. Each of these booklets describes specific actions that can improve health care of children with chronic conditions.

Larson, G. (Editor), 1986. *Managing the School Age Child with a Chronic Health Condition.* Pathfinder and the School Nurse Organization of Minnesota, DCI Publishing. 335 pages. This book is a practical guide for schools, families, and organizations. A family may find it useful to review and discuss chapters about its child's condition with school personnel.

Mitchell, J. 1980. *See Me More Clearly: Career & Life Planning for Teens with Physical Disabilities.* Harcourt Brace Jovanovich, New York, NY. 284 pages. A comprehensive guide for youth with disabilities. Includes a section titled "Charting Your Course: Life Career Skills."

National Center for Education in Maternal and Child Health (NCEMCH). 1989. *Reaching Out: A Directory of National Organizations Related to Maternal and Child Health.* 38th & R Streets, NW, Washington, DC 20057. This resource guide lists organizations by specific disease or disability.

National Maternal and Child Health Clearinghouse (NMCHC) 1988. *Publications Catalog.* 38th & R Streets NW, Washington, DC 20057. 22 pages. Catalog of publications available through NMCHC. Most of these publications are free. One section lists publications about children with special health care needs.

Pediatrics for Parents. This newsletter is written to help parents understand pediatrics and health care issues so they can become informed, active participants in their child's health care. 10 issues per year. Write or phone for subscription information: Pediatrics for Parents, 358 Broadway, PO Box 1069, Bangor, MD 04401. Phone (207) 942-6212.

Randall-David, E. 1989. *Strategies for Working with Culturally Diverse Communities and Clients.* Association for the Care of Children's Health. Washington, D.C. 96 pages. This guide is written to help professionals learn to provide culturally appropriate care to families and communities. It includes sections on assessing your own cultural heritage, learning about the community, working with culturally diverse groups, and using interpreters.

Routburg, M. 1986. *On Becoming a Special Parent: A Mini-Support Group in a Book.* Parent/Professional Publications, Box 59730, Chicago, IL 60645. Chapters on adjustment, equipment and toys, hospitals, respite, health care, medication, therapy, advocacy, individualized education program (IEP), and more.

St. Germaine, A. 1986. *Resource Manual for Physically Disabled Adolescents.* Gillette Hospital Interdependent Living Clinic, University of Minnesota Myelomeningocele Clinic. This manual contains Minnesota and national resources for youth. Topics include newsletters, funding sources, camps and special programs, social and recreational programs, counseling, transportation, residences, and transitional programs.

Segal, M. 1988. *In Time and With Love: Caring for the Special Needs Baby.* Newmarket Press, New York, NY. 192 pages. For families and caregivers of preterm and handicapped children ages birth to 3 years. Information is included about coping; nursing, feeding, and dressing; social skills; games and activities; discipline; and decision making.

United Cerebral Palsy of Minnesota. *Health Care Coverage and Your Disabled Child: A Guide for Parents.* 31 pages. This booklet answers many questions parents might have about health care coverage for their children. It describes types of insurances, HMOs, and alternative ways to finance health care.

Health Care Financing

There are many types of health care financing available to families with children with special health care needs. Each plan covers different services. Eligibility requirements also differ. Listed are some of the most common payment systems. Contact your local county human services office or the providing agency to find out if you are eligible for any of these.

Children's Health Plan (CHP)
444 Lafayette Road
St. Paul, MN 55155-3829
(612) 297-3862
(800) 652-9747 (Ask for Children's Health Plan)

The Children's Health Plan offers health care insurance for under insured or uninsured children 1 through 8 years old. After January 1, 1991, the plan will be available to children 1 through 17 years old. Coverage costs $25 per year, per child. Eligibility is based on income and family size.

Medical Assistance Program
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-3386
(800) 652-9747 (Ask for Medical Assistance)

Medical Assistance offers health care financing for families. Eligibility is based on income and family size. Children with chronic health conditions may qualify for full Medical Assistance benefits based on their income and assets alone under a waiver. For information, call your county human services office or the state office listed here. Local county human service agencies may also have funds under Title XX Social Service Programming, Family Subsidy, or Permanency Planning Grant.

Waivers

Waivers provide medical assistance benefits to children counting only the child's income and assets to determine eligibility. Expenses covered vary with each type of waiver.

Children's Home Care Option (TEFRA 134)
Medical Assistance is offered under the Children's Home Care Option or TEFRA. Children must be certified as disabled by the Social Security Administration or the State Medical Review

Team. Children are cared for at home. Eligible children have all regular medical assistance expenses covered.

Community Alternative Care (CAC)
The program offers home and community care services for chronically-ill children. Children must be residents of a hospital or be likely to need inpatient hospital care. Children are cared for at home. The program covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Community Alternatives for Disabled Individuals (CADI)
This program covers applicants to or residents of nursing care facilities. The person must be certified as disabled. Children are cared for at home. The program offers home and community care services for disabled individuals under age 65. It covers expenses for care that cost less than they would at an institution covered by Medical Assistance.

Home and Community Based Waiver for Persons with Mental Retardation or Related Conditions (MR/RC)
Individuals diagnosed with mental retardation or a related condition of any age are eligible. The person is cared for at home. This waiver covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Services for Children with Handicaps (SCH)

Minnesota Department of Health
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free, voice or TDD)

Services for Children with Handicaps offers financial help for health care to children with special health care needs. Eligibility is based on income and number of family members. SCH serves children from birth to age 21 years. Services for Children with Handicaps has district offices in Bemidji, Fergus Falls, Virginia, Duluth, Marshall, St. Cloud, Minneapolis, Mankato, and Rochester.

Notes:

Minnesota Department of Health
717 Delaware St. S.E.
P.O. Box 9441
Minneapolis, MN 55440